Newborn Screening Advisory Committee
Member Biographies

Ann Allen, Au.D., is an educational audiologist with Intermediate School District 917 and an on-call pediatric clinical audiologist at Children’s Hospitals and Clinics of Minnesota. As an educational audiologist, she has the opportunity to see firsthand how the presence and absence of early identification and prompt early intervention impact students with hearing loss in their educational environments. Her clinical audiology experience helps her to see the opportunities and challenges present in guiding children and their families through diagnosis and into intervention quickly. She sees communication with families and among professionals who serve children as key to the success of early identification and intervention programs.

Susan Berry, M.D., is Professor of Pediatrics and Genetics, Cell Biology and Development at the University of Minnesota and is Director of the Division of Genetics and Metabolism in the Department of Pediatrics and the Institute of Human Genetics. She received a B.A. in biochemistry (Rice University, 1975) and an M.D. (Kansas University, 1978). She did her residency in pediatrics (1978-1981) and fellowship in medical genetics (1981-1984) at the University of Minnesota. She has cared for children with inborn errors of metabolism throughout her medical career and has a longstanding interest in improvement in their care through early diagnosis and treatment.

Tania Daniels, P.T., M.B.A., is dedicated to patient safety and quality activities as Director of Health Policy at the Minnesota Hospital Association, a position she has held since October 2000. Ms. Daniels has been interested in quality improvement in the acute care setting since 1997 when she was the physical therapy supervisor at Fairview University Medical Center. Ms. Daniels has an interest in newborn screening for its potential to improve the quality of life and to improve health care quality through education and the use of evidence-based medicine.

Steve Johnson is a parent of a child with phenylketonuria (PKU). As a result of that experience, he has become very interested in the important role newborn screening plays in the lives of many people. A generation before his daughter was born, and before the adoption of the PKU screening test in Minnesota, children with PKU went undetected until irreversible damage had occurred to their intellectual development. These children often were institutionalized. In contrast, thanks to early detection and intervention, Mr. Johnson’s daughter graduated from college with a degree in cognitive neuroscience. Mr. Johnson has expressed hope that the work of the newborn screening advisory committee will make a difference in the lives of many others.

Marianne Keuhn is State Director of Program Services for the March of Dimes. The March of Dimes is the first national health organization to recommend that every baby born in the U.S. receive, at a minimum, screening for the same core group of nine metabolic disorders as well as hearing deficiency. Given that newborn screening provides a simple and inexpensive solution to potentially devastating problems, the March of Dimes feels that it is time for all states to make screening a top priority. The March of Dimes is proud to be a part of the Newborn Screening Program Advisory Committee and believes that the work it is doing will benefit all Minnesota babies.

Anthony Killeen, M.D., Ph.D., is the medical director of clinical laboratories at the University of Minnesota Medical Center, Fairview, in Minneapolis, and Associate Professor of Laboratory Medicine and Pathology. He received his medical degree from the National University of Ireland and his Ph.D. from the University of Minnesota. He is board certified in pathology and in genetics. Dr. Killeen has held leadership positions in clinical pathology at...
the national level, including chairing the College of American Pathologists chemistry resource committee. He served as an advisor to the Michigan Governor’s Task Force on Genetic privacy. He is a nationally recognized expert in the fields of clinical chemistry and molecular diagnostics, and has contributed to research in the area of congenital adrenal hyperplasia.

Jan Larson is a parent of a child with glutaric acidemia type I. Alex, born in 1993, was not diagnosed until age 3. Unfortunately, by that time he had already suffered some impairment of his gross and fine motor skills. Jan and his wife, Lib, therefore became supporters of expanding newborn screening and testified at a state Senate hearing in 2000. Although Alex is doing well in school, his physical limitations impact his daily life. Jan and Lib are therefore excited about the expansion of newborn screening and the very direct benefit to the children of Minnesota, and they are thankful for all the gifted individuals who are working so hard to identify and treat affected infants.

Julie Thompson Larson, B.S.N., M.S., is Director of the Birth Center at Regions Hospital in Saint Paul. She received her B.S.N. from the University of Wisconsin-Eau Claire in 1978 and her M.S. from the University of Minnesota in 1988. Since 1980, she has worked in the maternity department at Regions Hospital, as Staff Nurse for nine years, Clinical Educator for one year, Nurse Manager for sixteen years, Program Manager for two years, and Director for two years. She developed the Newborn Hearing Screening Program currently in place. She has worked on numerous hospital committees to promote the well-being of all women, infants, and their families. She lives in White Bear Lake with her husband and eighteen-year-old son. She also has three grown stepchildren, three granddaughters, and two grandsons. She is privileged to be a member of the Newborn Screening Program Advisory Committee and hopes to provide valued information from the hospital perspective.

Candace Lindow-Davies is the parent of a child who is profoundly deaf. Late in 2000, she was hired by Lifetrack Resources to develop a state-wide parent support program for families who have children with hearing loss. She began serving on the Minnesota Department of Health’s Newborn Hearing Screening Advisory Committee at that time. Her program provides consultation to Minnesota’s Newborn Hearing Screening program. Ms. Lindow-Davies also serves as co-chair of the Parent-to-Parent National Teleconference under the CDC’s National Newborn Screening Program. At the time her son was born, newborn hearing screening was not offered to healthy babies. Through her own experiences as a parent of a late-identified child and on behalf of the many families she serves, she strongly supports newborn screening, especially hearing screening, so that families have timely access to critical time-sensitive intervention services.

Richard C. Lussky, M.D., M. P. H., is Co-Medical Director of the Hennepin County Medical Center Newborn Intensive Care Unit and has twenty years of clinical experience in the care of newborn infants. He has witnessed first-hand the benefits of a comprehensive and coordinated state-wide newborn screening program. With the expansion of the panel of metabolic disorders screened, Dr. Lussky has experience with several infants who were saved from serious morbidity and potentially fatal complications related to inborn errors of metabolism. Dr. Lussky has expressed his feeling that it is a privilege to work with the Minnesota Department of Health and the Newborn Screening Program Advisory Committee.

Dorothy Markowitz, R.D., L.D., (a.k.a. “Dorothy the Dietitian”) of Fairview University Medical Center met her first phenylketonuria (PKU) patient at the University of Minnesota Hospital in 1976, beginning a fulfilling career in the nutrition management of inborn errors of metabolism. What started as a job became a passion. Ms. Markowitz has participated in initiating parent support groups, planning educational seminars, working on local newsletters, connecting families, and helping individuals find resources needed to follow through on recommended dietary treatments. Ms. Markowitz’s husband says that she will be attending PKU picnics until she is 80! During her nearly 30 years of practice, Ms. Markowitz has seen advances in treatment, development of improved specialty formulas and foods, and, most recently, continued expansion of newborn screening, all contributing to improved outcomes. Ms. Markowitz values the newborn screening advisory board as a voice for continued advancement in the early detection of, and the assured provision of follow-up for patients with, inborn errors of metabolism.
Dietrich Matern, M.D., is an associate professor of laboratory medicine at the Mayo Clinic College of Medicine. Prior to coming to Minnesota, he completed a pediatric residency in his native Germany (Albert-Ludwigs-University, Freiburg, 1992-97) and genetics fellowships at Duke University (1997-1999). He serves as co-director of the Biochemical Genetics Laboratory in the Department of Laboratory Medicine and Pathology and holds joint appointments in the Department of Pediatric & Adolescent Medicine and in the Department of Medical Genetics. Dr. Matern has a special interest in the early diagnosis of inborn errors of metabolism, particularly by application of tandem mass spectrometry. In the area of newborn screening, he is interested in the reduction of false positive results by second-tier assays using the original newborn screening blood spot sample and in determining the most efficient and effective approach to expand newborn screening to include lysosomal storage and other disorders.

Lou Mertz is the father of son born in 1999 who lives with cystic fibrosis (CF). He and his wife Pam struggled with their son’s health prior to his diagnosis. He was 5 months old, weighing only 10 pounds, and losing weight. He suffered through months of stomach pain, chronic bronchitis, RSV (respiratory syncytial virus) and was a very unhappy baby. Lou is also the Vice President of RespirTech, a medical device manufacturer of a High Frequency Chest Compression device for children and adults who suffer from cystic fibrosis, COPD (chronic obstructive pulmonary disease) and many other pulmonary diseases. Before the addition of newborn screening for CF, children went undiagnosed until symptoms of the disease became apparent to their parents and caregivers. Sometimes even that would take years, and in many cases children have suffered irreversible damage, which includes learning disabilities linked to malabsorption and nutritional issues. Within recent years, life expectancy for CF patients has grown to 35.1 years. With diagnosis at birth, Lou believes that number will definitely rise, simply by being able to immediately take advantage of the life-extending, preventative therapies now available through diligent research by the CF Foundation and CF Centers around the nation. In addition to serving on the Minnesota Department of Health Newborn Screening Program Advisory Committee, Lou is also a member of the board of directors for the Cystic Fibrosis Foundation, Minnesota chapter, and is Co-Chair of the Annual “Breath of Life” Gala for the CF Foundation. He is a member of the National Leadership Council of the Cystic Fibrosis Foundation and sits on the Parent Advisory and Advocacy Council for the Cystic Fibrosis Center at the University of Minnesota. Lou and his wife Pam have dedicated themselves to doing all that is possible to raise awareness of cystic fibrosis and to help raise funds to find a cure.

Stephen Nelson, M.D., is the director of the hemoglobinopathy program at Children's Hospitals and Clinics in Minneapolis and St. Paul. Dr. Nelson received his bachelor's degree in French from Randolph-Macon College in 1983 and his M.D. from Eastern Virginia Medical School in 1987. He completed pediatric hematology/oncology fellowship training at Duke University in 1993. Dr. Nelson has been working at the Children's Hospitals for 11 years and is devoted to improving the lives of children with sickle cell disease and thalassemia.

Amy Powers, M.S., C.G.C., is a genetic counselor at the Cystic Fibrosis Center at the University of Minnesota Medical Center, Fairview. She works closely with infants with positive CF newborn screening results, as well as individuals and families followed in the pediatric and adult CF clinics. She received a B.S. in Biology from the University of Michigan and M.S. in Genetic Counseling from the University of Pittsburgh. Past professional experiences include working in genetics laboratories studying ophthalmologic diseases, as well as providing clinical genetic counseling services for metabolic, mitochondrial, and CF clinics at Childrens Hospital Los Angeles and high risk prenatal services at the Center for High Risk Pregnancy in Pensacola, FL. Throughout her career she has maintained a special interest in educating and supporting families of infants and children with genetic conditions.

Michael Pryor, M.D., is a pediatric pulmonologist at Children's Hospitals and Clinics of Minnesota. He graduated magna cum laude from Creighton University in 1982 with his bachelor's degree in chemistry. Dr. Pryor graduated from medical school at the University of Nebraska College of Medicine and completed his residency training in pediatrics at Nebraska in 1990. He finished his fellowship training in pediatric pulmonology at the University of Minnesota in 1993, receiving a grant from the Cystic Fibrosis Foundation during his fellowship. Dr. Pryor has been working at Children's Hospital since 1991. He is the associate director of the cystic fibrosis center, and provides care for a wide variety of children with complex respiratory disorders. His primary clinical interests include asthma, chronic lung disease of infancy, and cystic fibrosis.
Piero Rinaldo, M.D., Ph.D., is a pediatrician and a professor of laboratory medicine at the Mayo Clinic College of Medicine. He serves as chair of the Division of Laboratory Genetics, director of the Biochemical Genetics Laboratory in the Department of Laboratory Medicine & Pathology, and holds joint appointments in the Department of Pediatrics & Adolescent Medicine and in the Department of Medical Genetics. Dr. Rinaldo has devoted more than 20 years of clinical and research work to the study of a wide range of metabolic disorders, newborn screening, and metabolic causes of sudden and unexpected death. He is a member of the Advisory Committee to the Secretary of Health and Human Services for heritable disorders in newborns and children.

Kyriakie Sarafoglou, M.D., Director of the Center for Congenital Adrenal Hyperplasia (CAH) and Gonadal Development Disorders, is a pediatric multi-specialist (Endocrinology, Inborn Errors of Metabolism and Human Genetics) active in patient care, clinical research, and education at the University of Minnesota Medical School. Dr. Sarafoglou completed her pediatric residency at the University of Texas San Antonio Health Science Center, fellowship in pediatric endocrinology at Weill Medical College of Cornell University, and fellowship in human genetics and metabolism at New York University School of Medicine. She is a strong advocate of the Newborn Screening Program and the collaboration between the state and medical community in developing programs that screen for early detection of rare disorders and offer follow-up care for these patients with inborn errors of metabolism. Her current research focuses on the monitoring and treatment of patients with CAH, and she is the editor of a McGraw-Hill textbook (Essential Pediatric Endocrinology and Inborn Errors of Metabolism) scheduled for release in Fall 2006.

Kevin Sheridan, M.D., is a pediatric endocrinologist staff physician at Gillette Children's Specialty Healthcare in St. Paul and an internal Medicine Endocrinologist at Regions Hospital in St. Paul. Dr. Sheridan received his bachelor's degree in biology from Cornell University in 1974 and his M.D. from the University of Minnesota in 1986. He completed an internal medicine and pediatric residency at West Virginia University and a combined endocrinology fellowship at the University of Minnesota. Dr. Sheridan has been working at HealthPartners since 1996 and Gillette since 2001 and cares for children with complex bone and other endocrine disorders, several of which are found on the newborn screening panel. He is interested in chronic endocrine disorders which span the life cycle.

Kathy Stagni is a parent of a daughter born in 1988 with propionic acidemia (PA), an inborn error of metabolism, whose disorder was not diagnosed at birth and who suffered irreversible brain damage as a result. Since 1998, Kathy has dedicated herself to the support of children with special needs and their caregivers. She is Administrative Director of the Organic Acidemia Association (www.oaanews.org); a member of the Minnesota Department of Health Newborn Screening Advisory Committee; and is active in Special Olympics and adapted sports in the local community.

Kathy Teufert, R.N., C.N.P., is a neonatal and pediatric nurse practitioner employed by Minnesota Neonatal Physicians to provide inpatient medical care to selected medically-fragile infants at Children’s Hospitals and Clinics – Minneapolis. She became interested in newborn screening while caring for these complex patients who often had more than one newborn screen performed and results that were at times confusing to interpret. How parents are educated regarding study results, the need for and timing of follow-up, and the need to improve how study results are documented are areas of specific interest to her. She welcomes the opportunity to assist the Minnesota Department of Health and the Newborn Screening Program Advisory Committee to promote evidence-based best practices for families and streamlined educational services.